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### Core principles for involving people with dementia in research

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## **CORE PRINCIPLES FOR INVOLVING PEOPLE WITH DEMENTIA IN RESEARCH: INNOVATIVE PRACTICE**

SCOTTISH DEMENTIA WORKING GROUP RESEARCH SUB-GROUP

### **Abstract:**

The Scottish Dementia Working Group Research Sub-group is part of the Scottish Dementia Working Group, an internationally renowned campaigning group of people with dementia. We co-created our core principles for involving people with dementia in research between September and December 2013.

The principles address six areas: (i) how people with dementia are valued and involved in research (ii) lived experience as valid knowledge (iii) physical and emotional safety (iv) accessibility of all aspects of research (v) training for researchers (vi) the impact of our experiences of time on research processes.

Through our core principles, we challenge researchers across all disciplines to re-consider how we and other people with dementia are involved in research as well as how knowledge in dementia research is created.

### **Keywords:**

People with dementia, participation, research

## **Introduction**

Since 2001, the Scottish Dementia Working Group has been at the forefront of a growing movement towards people with dementia influencing decisions about their lives. Our work impacts positively not only on our own lives but also on the lives of people with dementia internationally.

In August 2013, the SDWG established a research sub-group. There were two main reasons for establishing the group. Firstly, the research sub-group provides a forum in which the large volume of requests coming into the SDWG to collaborate in research can be considered in an informed way. Secondly, the research sub-group provides a forum for the quality of relationships between researchers and the SDWG to be monitored and developed in ways which leads to meaningful research involvement for all people with dementia as well as the SDWG.

There are 15 members of the research sub-group, including some of the founding members of the SDWG. Between September and December 2013, in collaboration with Sarah Keyes and Nick Jenkins from the University of Edinburgh and supported by Dot Weeks and Liz Taylor, we co-created the core principles for involving people with dementia in research.

We began by discussing our individual research experiences and views, for example our experiences of good and bad research. We then worked together as a group to construct a model of a '*dementia friendly research community*'.

This enabled us to explore three areas:

- Whose priorities?
- Who benefits?
- How do we stay safe?
- Sarah and Nick then developed these views and experiences into the six areas which form the basis of the core principles.

Following this, Sarah and Nick developed transcripts of our discussions into statements and sub-statements which we collectively ranked and refined into the core principles as they appear below. We found blocking the text into separate boxes made it easier to read. We also found that it was easier to read if the headings, principles, and 'what this means' sections were separated into different colours. For an accessible version of the principles, go to:

<http://coreprinciplesdementia.wordpress.com>.

## **Key View/Experience one: I never heard what happened**

### **Principles:**

- We want to be valued, and to be kept involved and informed
- Good research gives you something after the end
- There is a risk that people with dementia taking part in research can be 'used' by researchers
- Research should start from a place of seeking positive and lasting change in our lives, and in the lives of people with dementia in the future
- It usually takes several years and more than one research project for positive and lasting change to happen

### **This means that:**

- ✓ Researchers should ask people with dementia how they want to be involved in research, including at what points and in what ways they want to be updated. Different people will have different views on this
- ✓ We want researchers to come back and tell us the outcome of research that we have been involved in. Please be honest and don't bury 'bad' findings
- ✓ For many of us, keeping us involved means keeping our families (or a trusted person who we nominate) involved and informed too
- ✓ In order for research to make a full impact, professionals and others in our communities need to be involved and informed about the outcomes of research in ways which reflect their involvement in our lives

## **Key View/ Experience two: knowledge comes from all sorts of places**

### Principles:

- People with dementia experience it twenty-four hours a day, seven days a week
- We are often involved in answering research questions, but we are not often asked about research priorities
- Research priorities shouldn't just be set by researchers, but they shouldn't just be set by people with dementia either: we need to work together in influencing knowledge about dementia
- People with dementia often have to be researchers themselves, for example finding out what support is best

### This means that:

- ✓ It is important that researchers use the views and experiences of people with dementia as 'knowledge'
- ✓ The process of setting research agendas should happen in a mutual relationship between people with dementia and researchers
- ✓ This should include people with dementia being involved in setting research priorities, for example researchers asking people with dementia what a positive outcome would look like for them
- ✓ Researchers should create opportunities for us to develop our research skills so that we can be involved in influencing knowledge about dementia
- ✓ When considering all of the above, researchers should consider creative methods and new ways for creating new knowledge in partnership with people with dementia

## **Key view/Experience three: we need to be in a safe and secure environment**

### **Principles:**

- It is important that everyone taking part in research, especially people with dementia, are physically and emotionally safe
- Each day, and different times in each day, can be different for people with dementia
- Being asked to go back and remember unhappy or difficult times can make us feel the old pain, emotion and bad memories
- It is also important that researchers are physically and emotionally safe

### **This means that:**

- ✓ Researchers should find out each time we meet how we are and what support we need that day (including if things were to go wrong) This includes making sure that we are emotionally well and get home from meetings safely
- ✓ Also find out if there is someone else we would like to have with us when we are taking part in research
- ✓ People with dementia taking part in research should always be offered counselling or emotional support
- ✓ Find out where are 'safe zones' are (both physically and emotionally) and meet us there
- ✓ Be aware that research has the potential to take people with dementia outside of their 'safe zones' and be ready to respond
- ✓ Researchers should be aware of their own 'safe zones' and know where to go/not go (physically and emotionally)

## **Key View/Experience four: keep it simple.....less is best**

### **Principle:**

- All communication about research should be presented to us in a language we will understand
- There is a risk that language used to refer to people with dementia is derogatory and reinforces stigma

### **This means that:**

- ✓ It is important that researchers speak in layman's language. Please keep in simple
- ✓ Researchers should explain terms each time they use them. Don't use abbreviations and acronyms
- ✓ People with dementia should always receive a summary of the final report in simple, understandable language
- ✓ All documents about research, for example proposals, information sheets and consent forms that researchers want people with dementia to engage with need to be in clear, accessible language
- ✓ We are going to develop some specific guidelines for making documents easier to read
- ✓ Researchers should use language which is supportive of people with dementia and consider ways in which language can offend people with dementia



## **Key view/experience five: why should anyone be let loose, who hasn't had the training.....?**

### Principles:

- All people doing research with people with dementia need to be dementia aware. If you do not have formal training, that doesn't matter, but you must have these attributes:
  - empathic (not sympathetic);
  - compassionate;
  - knowledgeable;
  - un-patronising;
  - tolerant;
  - understanding;
  - respectful (our time is just as important as yours);
  - Being dementia aware also means giving us time to think and reflect and respond to questions, using appropriate language; being ethical and doing what you say you will

### This means that:

- ✓ We are going to create some training resources for researchers. They should read these before coming to meet with us as a group. These will include training about dementia and about how researchers should support people with dementia
- ✓ It is important for researchers to know that we are all different. This includes the fact that there are lots of different types of dementia that can affect people differently

## **Key View/experience six: keep to 'dementia time'**

### Principles:

- There is no guarantee that we will remember the past in the order it happened
- We need regular breaks when taking part in research interviews or groups
- Sometimes life becomes so chaotic that we might need to take a break from a research project, or withdraw altogether

### This means that:

- ✓ Researchers need to consider 'dementia time' in their expectations of research, including finding out the best time and how each individual keeps track of time
- ✓ Researchers should always re-cap on previous conversations or interviews each time they meet with people with dementia
- ✓ It is important that researchers find out from us and from people who we trust what is going on in our lives, especially if they are getting in touch after a gap in contact
- ✓ It is important that researchers remind us the day before that they will be meeting with us, using the communication that we indicate is best and arrive at the time they said they would
- ✓ Researchers should not stay for longer than agreed, unless the person with dementia invites them to

## **Conclusion**

We will be using the core principles as a standard for future research involving the SDWG. We continue to meet every two months, and have developed an application form, based on the principles, for researchers wishing to work with the SDWG. Our hope is that the principles will have much wider application and impact than their use by the SDWG. The experiences and views expressed and the process through which the principles were co-created mean that these principles are a site for dialogue through which everyone involved in dementia research could strive to develop and maintain a dementia friendly research community. Our core principles challenge researchers across all disciplines to re-consider not only how people with dementia are involved and valued in research but also how knowledge is constructed in dementia research.

FOR FURTHER INFORMATION ABOUT THE CORE PRINCIPLES:

[HTTP://COREPRINCIPLESDEMENTIA.WORDPRESS.COM](http://coreprinciplesdementia.wordpress.com)

FOR FURTHER INFORMATION ABOUT THE SCOTTISH DEMENTIA WORKING GROUP:

[HTTP://WWW.SDWG.ORG.UK/](http://www.sdwg.org.uk/)

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